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**POSTPARTUM PSYCHOSIS
AND SOCIAL SUPPORT IN
UGANDA**

THE EFFECT OF FAMILY PSYCHOEDUCATION

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Empowerment is not a destination but a journey
(WHO, 2010)

ABSTRACT

Background: Postpartum psychosis is a rare but severe psychiatric condition that affects not only the mother but the whole family. The standard of care for this condition in Uganda is mainly medical treatment. The role of adjunctive psychosocial treatments for this condition on social support that is crucial when mothers develop psychosis is not well researched in Uganda.

Main objective: To investigate the effect of family psychoeducation (FPE) on perceived social support of mothers with postpartum psychosis (*amakiro*) in central Uganda

Methods: Fourteen Focus Group Discussions (FGDs) and 30 in-depth interviews were conducted among mothers with and without psychosis, their caregivers, nurses and midwives, and Traditional Birth Attendants (TBAs) to explore existing knowledge on perceptions on postpartum psychosis in Uganda (Study I). In Study II, we adapted the Multidimensional Scale of Perceived Social Support (MSPSS) in a cross-sectional design with consecutive recruitment of 240 postpartum mothers. Analysis of reliability and validity using cronbach alpha and principal component analyses were performed. In Study III, a section of the Family Psychoeducation Implementation Resource Toolkit was adapted to incorporate Ganda cultural issues related to postpartum psychosis. Postpartum mothers with psychosis, their caregivers, psychiatric nurses, and psychologists were the participants. In-depth interviews, consultative meetings and a FGD were carried out together with observation. Through discussions and drawing consensus, FPE was adapted. In a Randomized Controlled Trial (RCT) of 104 postpartum mothers and their caregivers, FPE was carried out on the intervention group ($n = 53$) of mothers for 3 months on a weekly basis for 2 hour sessions (Study IV). Data about perceived social support at baseline and after intervention were collected. Intention to treat analysis using analysis of covariance and moderation analysis were used.

Results: Perceptions on postpartum psychosis that were documented in the 1970s are still prevalent in the setting (Study I). Using cronbach alpha, the MSPSS yielded internal consistency of .83. Principal component analysis generated high loadings on all subscales (Study II). Potential improvements in FPE were identified both in the process and the content of the program. Whereas the basic principles underlying the process of carrying out FPE remain the same, changes in the content were proposed and these reflected the social cultural and economic reality of the population (Study III). After adjusting for baseline perceived social support, postpartum mothers in the interventional group had higher levels of perceived social support than the control group ($F = 6.31$, $p = .01$) and a moderate effect of .35 (Study IV).

Conclusion: FPE has a positive impact on the perceived social support of mothers with postpartum psychosis in central Uganda and it might be one way by which cultural perceptions can be demystified.

Key words: Adaptation, Family psychoeducation, Postpartum psychosis, Social support

LIST OF PUBLICATIONS

The thesis is based on the following sub studies which will be referred to by their roman numerals.

- I. Nakigudde J, Airaksinen E, Musisi S, Muhwezi W, Neema S, Mirembe F. Perceptions regarding postpartum psychotic illness in two districts in Central Uganda. *World Cultural Psychiatry Research Review*. 2010, 57-69
- II. Nakigudde J, Seggane M, Ehnvall A, Airaksinen E, Ågren H. Adaptation of the Multidimensional Scale of Perceived Social Support in a Ugandan setting. *African Health Sciences*. 2009; 9, S35-S41
- III. Nakigudde J, Airaksinen E, Mirembe F, Musisi S, Ehnvall A. Family psychoeducation for postpartum mothers with psychotic illness in Uganda: a cultural sensitivity and appropriateness study. *Submitted Manuscript*
- IV. Nakigudde J, Musisi S, Airaksinen E, Ehnvall A, Muhwezi W, Buwembo D, Huang K, Mirembe F. Effects of short term intensive family psychoeducation treatment on perceived social support of postpartum mothers with psychosis: a randomized trial. *Manuscript*

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LIST OF ABBREVIATIONS

ANCOVA	Analysis of covariance
CDC	Center for Disease Control
DSM	Diagnostic Statistical Manual of Mental Disorders
FGD	Focus Group Discussion
FPE	Family Psychoeducation
GDP	Gross Domestic Product
IMR	Infant Mortality Rate
MINI	Mini International Neuropsychiatric Interview
MSPSS	Multidimensional Scale of Perceived Social Support
PI	Principal Investigator
TBA	Traditional Birth Attender
PNFP	Private Not for Profit
USAID	United States Agency for International Development
WHO	World Health Organization

OPERATION DEFINITIONS

Adaptation: Included strategies that were used to translate the Multidimensional Scale of Perceived Social Support into the target language- Luganda, the process of testing its psychometric properties on the Ugandan population and the comparison of these properties with the countries where the instrument has already been used.

Amakiro: A broad local term for illnesses that afflict postpartum mothers in Central, Western and some parts of Eastern Uganda.

Caregiver: A Caregiver is the person who spends the most time and effort caring for the mother.

Family: A group of individuals who are related by affection, kinship, dependency or trust.

Family Psychoeducation: Information and education that an individual receives about an illness which causes Psychological distress.

Lubaale: A group of dead ancestors' spirits that are of the same lineage. They are perceived to be protective but when begrudged they can cause illness including mental illness

Postpartum period: A period after birth when a mother adjusts physically and psychologically to the process of childbirth. In most studies, this period lasts up to 8-12 weeks but for purposes of the study it will be extended to 6 months to take into account the extended period mothers may take before they present to mental health facilities when seeking for alternatives to western medicine.

Psychotic illness: This is a severe psychiatric illness that comprises of a distortion of reality with hallucinations, often visual or auditory, and or delusions. This was used interchangeably with psychosis.

Social Support: This is the tangible material, intimate and emotional interaction that a recipient receives from a provider.

1 INTRODUCTION

The perceived cause of severe psychiatric illness in Uganda is culturally attributed to supernatural causes such as ancestral spirits (Orley, 1970; Abbo et al, 2008). Severe psychiatric illness with psychosis during the postpartum period in the Ganda culture of Uganda has been culturally ascribed to the immoral behavior of the postpartum mother while pregnant (Cox, 1979). To a lesser extent postpartum psychosis of the mother has been attributed to the promiscuity of the male spouse of the postpartum mother (Cox, 1979; Neema, 1994). Underlying the above assumptions is the idea that the postpartum mother is guilty and therefore is being punished for her immoral behavior by the gods especially that there may be paternity issues regarding the newborn (Cox, 1999). When the postpartum mother is aware that she has not been involved in immoral behavior, then she is still disadvantaged because the assumed cause is now her promiscuous partner. She feels a sense of betrayal by the partner. By and large, the partner is also warranted to feel betrayed by the postpartum mother. The cultural perceptions regarding postpartum psychosis place an emotional burden on the postpartum mothers, their partners and other caregivers at a critical time when they are already distressed by the illness.

Empowering people with mental health problems and their caregivers is one of the World Health Organization's (WHO) agenda in promoting mental health. WHO has put up a framework by which empowerment indicators of patients and their families can be implemented. Among these indicators are access to appropriate and adequate information and education by patients and their families regarding a mental health condition that afflicts the patient (WHO, 2010). Family psychoeducation (FPE) that provides information and educates the patient and the caregiver on the nature of a psychiatric disorder that the patient has is one of the programs by which the WHO empowerment indicators of providing information and education can be realized. The provision of information, education and support to mothers with postpartum psychosis and their caregivers in order to demystify perceptions regarding postpartum psychosis in Uganda is the basis for this thesis.

2 BACKGROUND

2.1 POSTPARTUM PSYCHIATRIC ILLNESSES

Psychiatric illnesses in the postpartum period lie along a continuum of events. At one extreme end are the postpartum blues which are prevalent in about 50% to 70% of postpartum mothers (Robinson & Stewart, 1986). Postpartum blues may present with mild depressive symptoms which resolve spontaneously. They commonly occur during the first couple of weeks after delivery (Prabhu et al, 2005). Depressive disorders in the postpartum period seem to be the next prevalent mental illnesses during this period. These may occur during the first 2 to 3 months in the postpartum period. Their onset is insidious. Depressive disorders in the postpartum period can be severe with individuals experiencing suicidal ideations and homicidal ideas. Postpartum depression has been shown to have a prevalence range from 8 to 15% (Prabhu et al, 2005; Robinson & Stewart, 1986). In a study done in a peri-urban Ugandan setting, the prevalence of major depression in the postpartum period was estimated at 6.1% (Nakku et al, 2006). A more severe form of postpartum psychiatric illness is that which presents with delusions and or hallucinations; the psychoses. These have an incidence of 1 to 2 per 1000 women (Robinson & Stewart, 1986; Oates, 2003). Their onset is sudden and commonly occurs within the first 4 weeks of the postpartum period.

Although the sudden hormonal changes that a mother undergoes after birth has been given as a possible cause of the development of postpartum psychosis (Spinelli, 2009), there is indication through formal diagnostic assessment in clinical practice that postpartum psychoses are mostly of an affective nature presenting with depression or manic symptoms (Brockington et al, 1981; Meltzer & Kumar, 1985) and genetic evidence links them to bipolar disorder (Coyle et al, 2000). New mothers with a known psychiatric history of bipolar disorder have been shown to have an increased 40% risk of developing recurrent postpartum psychosis. It is also estimated that there is a 50% risk for women with bipolar disorder to suffer from postpartum psychosis (Robinson & Stewart, 1986). To a lesser extent postpartum psychoses may manifest as schizophrenic or organic states (Robinson & Stewart, 1986).

Psychoses in the postpartum period are characterized by various behavioral, affective and cognitive signs and symptoms dependent on their origin. In psychoses with depression, a mother may have psychomotor retardation, disturbances in sleep and appetite, guilt, feelings of worthlessness, delusions and or hallucinations, suicidal or homicidal thoughts. In psychoses with mania, there is hyperactivity, less sleep, excitement, feelings of grandiosity, irritability and poor insight. Psychoses of the schizophrenic form may present with motor retardation or agitation sometimes with catatonic features, inappropriate affect, thought disorder, delusions, and or hallucinations and poor insight (Robinson & Stewart, 1986). In psychoses of organic origin, mothers may present with delirious states (Spinelli, 2009; Brockington, 2006).

Box 1. Signs and symptoms of postpartum psychosis.

2.2 CONSEQUENCES OF PSYCHOSES IN THE POSTPARTUM PERIOD

Rare though the disorder is it is known to carry severe legal and social consequences. Homicidal ideas go together with infanticide thoughts of wanting to harm the newborn and research shows that this occurs in about 4% of women with postpartum psychosis (Parry, 1995). In their psychotic state postpartum mothers have been known to smother and strangle their newborns, kill other children and sometimes progress to making attempts on their own lives (Spinelli, 2009). This subsequently carries social stigma and also has legal implications because few understand that the mother at this time has poor insight and maybe experiencing delusions or even hallucinations. Often postpartum mothers have been charged with murder (Spinelli, 2009) instead of undergoing psychiatric treatment. Apart from legal and social consequences, research has shown that infants of postpartum mothers with psychosis experience delays in reaching developmental milestones (Robinson & Stewart, 1986), and may suffer from a disrupted mother-infant relationship (Brockington, 2004).

2.3 POSTPARTUM PSYCHOSIS PERCEPTIONS IN CENTRAL UGANDA

Psychotic illness gives rise to behavioral problems. Commonly family members will recognize the problem but they may not be aware that the patient lacks insight. In central Uganda, an exploration of postpartum psychotic illness locally known as *amakiro* was carried out and some of the illness symptoms included the mother wanting to harm the infant. The study findings showed that there was a cultural attribution for the cause of this postpartum psychiatric illness; if a mother had been promiscuous during pregnancy then it was reported that she would develop this type of mental illness (Cox, 1979). Whereas lay perceptions attribute postpartum psychosis causation to promiscuity (Cox 1979), scientific evidence points to other etiological factors (Kaplan & Sadock, 2000).

2.4 SOCIAL SUPPORT

Social support has been described in various ways. Some of the early definitions describe social support as one's belief that he or she is cared for, loved and belongs to a social network (Cobb, 1976). It has been described as a relationship transaction between a provider and a recipient. The recipient is the beneficiary in this relationship (Brownell & Shumaker, 1984). The support can be in form of information, financial assistance or any construct that satisfies the individual's social needs such as self-esteem, affiliation, approval and moral support (Heitzman & Kaplan, 1988). As a psychological concept, social support comprises of material or instrumental help which is the provision of tangible materials in the form of money, other materials, and intimate interaction. It also embraces behaviors such as listening, caring, understanding and a show of esteem, offering of advice, and guidance. Social support is described as including the provision of feedback about one's behavior, thoughts or feelings and the positive social interaction for the purpose of fun and relaxation (Barrera, & Ainalay 1983). Social support has been described comprehensively by the WHO as the availability of help to an individual or group from within a community setting that acts as a buffer against stressors and is a positive resource which enhances quality of life (WHO, 1998).

Although social support has been described differently and there seems to be no consensus on one definition, the categories of social support have been widely accepted upon as have been the types of social support. Social support has been categorized into emotional support which is mostly from family and friends. This includes caring, concern, love and trust. Appraisal support is about information provision and is commonly evaluative. Then there is information support is another category and this includes guidance on how to respond to life demands. Finally there is instrumental support. This encompasses the provision of material support like money (Barrera & Ainalay, 1983; House, 1981; Center for Disease Control (CDC), 2005).

Social support can be of two types; provided or perceived (MINDFUL database, 2008; CDC, 2005). Provided social support is the objective social support that is actually received by a recipient while perceived social support is the subjective measure of availability of support. Perceived social support is a sense that one has that support is available in case one needed it. This thesis is based on the subjective perceived social support for mothers with postpartum psychosis.

2.5 FAMILY PSYCHOEDUCATION

Stressors within the environment or psychosocial issues greatly influence the course of psychiatric illness. Commonly psychosocial stressors may trigger the onset or relapse of a mood disorder. Ensuring that psychosocial issues are understood within the context of an illness can help improve on treatment outcomes. Research findings have shown that psychiatric patients with a mood disorder who receive FPE have a better treatment outcome than those without (Griswold and Pessar, 2000). Findings of a randomized controlled trial, showed that psychosocial treatment that involved the family in the treatment plan of patients with schizophrenia enhanced patients' rehabilitation (McFarlane et al 2003).

FPE is a psychosocial treatment model that provides information, education and support to families many times including the patient on an illness that causes them distress for purposes of treatment and rehabilitation (Goldman, 1988). FPE endeavors to educate individuals on the nature of a specific illness, its etiology, the precipitating and predisposing factors, the treatment options and the recognition of symptoms and signs of the illness. It therefore works by improving the knowledge of patients and their families for a specific illness. It creates a favorable environment for understanding the importance of biomedical compliance, provision of social support to the patients, and the need for the prompt review in case of relapse. It helps families and individuals overcome myths and cultural beliefs for the specific illnesses, hence it provides information that allows individuals to adapt to the illness appropriately. FPE research shows that there is improved functional outcome in individuals that have been exposed to this education with improved wellbeing and greater employment outcomes (McFarlane et al 1996). Several other studies have reported positive outcomes of FPE. Psychoeducation on Korean American families for individuals with psychotic illnesses showed improved coping skills, enhanced empowerment in dealing with crises, and a significant decrease in stigma (Shin & Lukens, 2002). Improved compliance, recognition of mental disturbances and better family/clinician partnership were registered in the intervention group of FPE in China (Xiang et al, 1994). Apart from FPE showing positive outcomes, it has also been deemed cost effective (Vieta et al, 2009). In Spain FPE targeting caregivers

exclusively has had positive results on patients' longer relapse free intervals and a decrease in the number of patients with mood recurrence (Reinares et al, 2007).

2.6 THE BUFFERING HYPOTHESIS

The buffering hypothesis states that in the event of a stressor, any variable that helps to alleviate stress acts as a buffer (Cohen & McKay, 1984). In the event of postpartum psychosis, the lay perceptions regarding postpartum psychosis come into play (see Figure 1). They act as the antecedents to lead to low social support by the primary caregivers of the postpartum mother; the primary caregiver is stressed and feels burdened because she or he thinks that the woman has been promiscuous and hence guilty. If caregivers ascribe responsibility of the illness to the postpartum woman as has been reported (Cox, 1979) then the primary caregivers may not offer the necessary social support to the mothers with psychosis. In this thesis FPE was the intervention in which information and education were provided to postpartum women and their caregivers to help alleviate their distress. It was hypothesized that FPE would act as a buffer and hence improve perceived social support of the postpartum mothers by demystifying perceptions regarding causes and treatment for the illness and by providing support in this particular Ugandan setting (see figure 1).

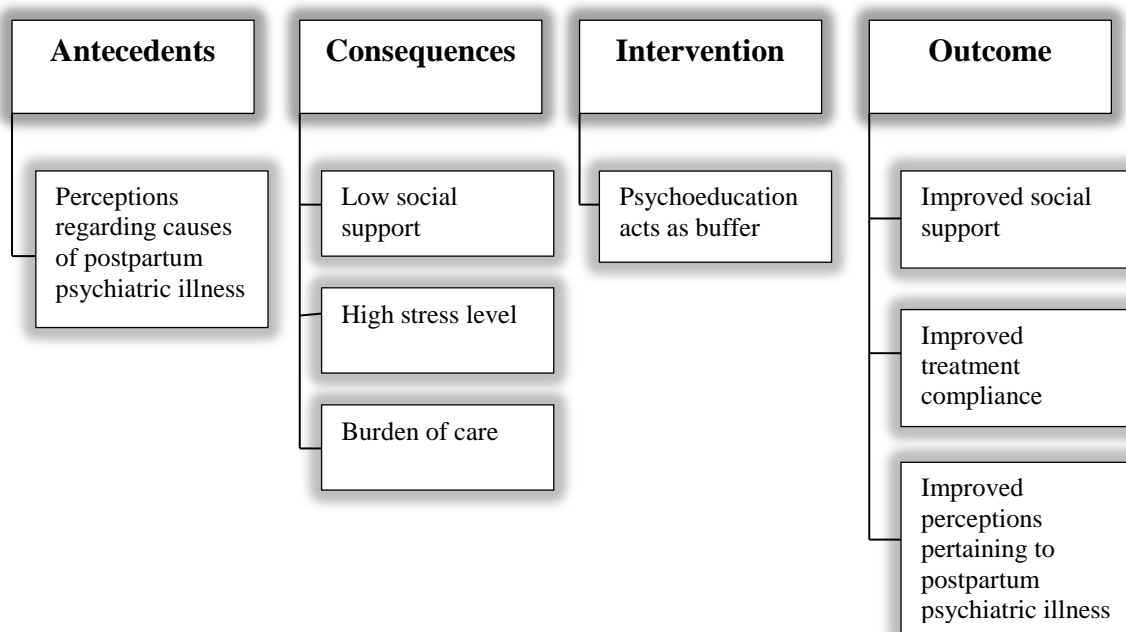


Figure 1. A conceptual framework of an overview of the buffering hypothesis

2.7 RATIONALE FOR STUDIES

Psychiatric illness causes stress to the family (Fadden et al, 1987). There is always a disruption of relationships with family when individuals develop psychiatric illness. In the course of the illness and due to the distress, listening which is a component of social support between the family and the patient is disrupted. Listening, understanding and appreciation of issues become harder both for the patient and the family. Feelings of family members and the patient may be misinterpreted and the concerned individuals feel uncared for and

unsupported. Care and support may thus be negatively influenced by the lack of communication and provision of information about the psychiatric illness.

The first three studies in this thesis were all pre-requisites for achieving the overall aim of assessing the effect of FPE in the perceived social support of mothers with postpartum psychosis. Study I which was qualitative in nature explored the community's perceptions regarding postpartum psychosis and this helped us to gain insight into what the community perceived to be the causes and possible treatments for psychotic illness in the postpartum period. The derived information was later used in the preparation of Study III.

Study II was an adaptation of the MSPSS. If perceived social support of the postpartum mothers was to be measured during Studies III and IV, it had to be assessed with a scale that was reliable and valid for the specific population of postpartum women. Since there was scanty information on the reliability and validity of this scale in an African setting, we investigated the psychometric properties of the MSPSS in this population before using it.

Study III explored how FPE developed in the west could culturally be made sensitive and appropriate for postpartum mothers with psychotic illness in the Ugandan setting. We drew on information obtained from study I. Different stakeholders with a special interest in severe psychiatric illness in the postpartum period were brought together to work on appropriate changes in a FPE program intervention that was to be used on postpartum mothers in Study IV. In study III we pilot tested the adapted FPE program that was used in Study IV.

Finally, in Study IV a randomized controlled trial we used all information obtained from the three previous studies to guide the process. This enabled us to reliably carry out FPE as an intervention in this population with unique needs and also to reliably measure perceived social support as an outcome in Study IV.

The rationale for these studies was to determine whether the provision of information and education regarding postpartum psychosis through FPE would enhance the perceived social support of postpartum women who are culturally blamed for the condition. The benefits of FPE have been researched comprehensively. Are there any more benefits to FPE such as improved social support? We hoped that the hypothesized positive outcomes in this efficacy study can lead to an effectiveness study. This should in turn be a basis for influencing policy on incorporating psychological interventions specifically FPE in the standard care of postpartum mothers with psychiatric illness.

3 GENERAL AIM

The aim of the thesis was to investigate the effect of FPE in family social support of postpartum mothers with psychotic illness (*amakiro*) in central Uganda.

3.1 SPECIFIC AIMS

- I)** To explore the perceptions of postpartum mothers with and without psychosis, their caregivers, and those involved in service delivery regarding postpartum psychosis.
- II)** To adapt the Multidimensional Scale of Perceived Social Support and test its psychometric properties in a Ugandan setting.
- III)** To explore how FPE could culturally be made sensitive and appropriate to cater for postpartum women with psychosis in a Ugandan setting.
- IV)** To investigate the role of the adapted FPE on the perceived social support of postpartum mothers with psychosis in a Ugandan setting.

4 MATERIAL AND METHODS

An overview of an intervention chain sequentially points out the progress of the research in the thesis from the point of exploring existing knowledge, adapting an outcome tool, preparing an intervention tool and finally carrying out the intervention (see Figure 2). It also gives an overview of the research questions and a summary of the research designs, setting, and participants for the different sub studies.

4.1 STUDY SITES

The data collection was carried out in two districts in central Uganda; Kampala and Mukono (Figure 3). Kampala is the capital of Uganda and is surrounded by Mpigi and Wakiso districts in the north, east, and west and, Lake Victoria in the south. The main languages spoken are predominantly Luganda and English. At the time of the data collection, Mukono was one big district in central Uganda. It shared borders with Jinja district in the east, Kayunga in the south, Luweero in the northwest, Kampala and Wakiso in the south west and Lake Victoria in the south. The district covered an area of 11,764 sq km and had a population of 807,923. It was the 5th most populated district in Uganda. It has since then been subdivided into smaller districts.

Uganda has a total area of 240,000 square km, with a population of 34,600,000. The population growth rate is 3.57%, birth rate is 47/1,000, and death rate is 12/1000. The infant mortality rate (IMR) is 62.47 per 1000 live births and the crude death rate is 9.8 per 1000 people. Uganda has a high fertility rate of 6.7 children per woman. The women of reproductive age constitute 23% of the population and women start having children at a young age with 25% of the deliveries being among teenage girls. The Ugandan population is young with most of the population (49%) between the ages of 0-14 years. It is predominantly an agricultural country with over 80% of the workforce employed in agriculture. Coffee is the most important export. Uganda has a national Gross Domestic Product (GDP) per capita of US \$ 1,200 and 35% of the population lives below the poverty line (CIA- World Fact book, 2010).

Box 2. A brief background about Uganda.

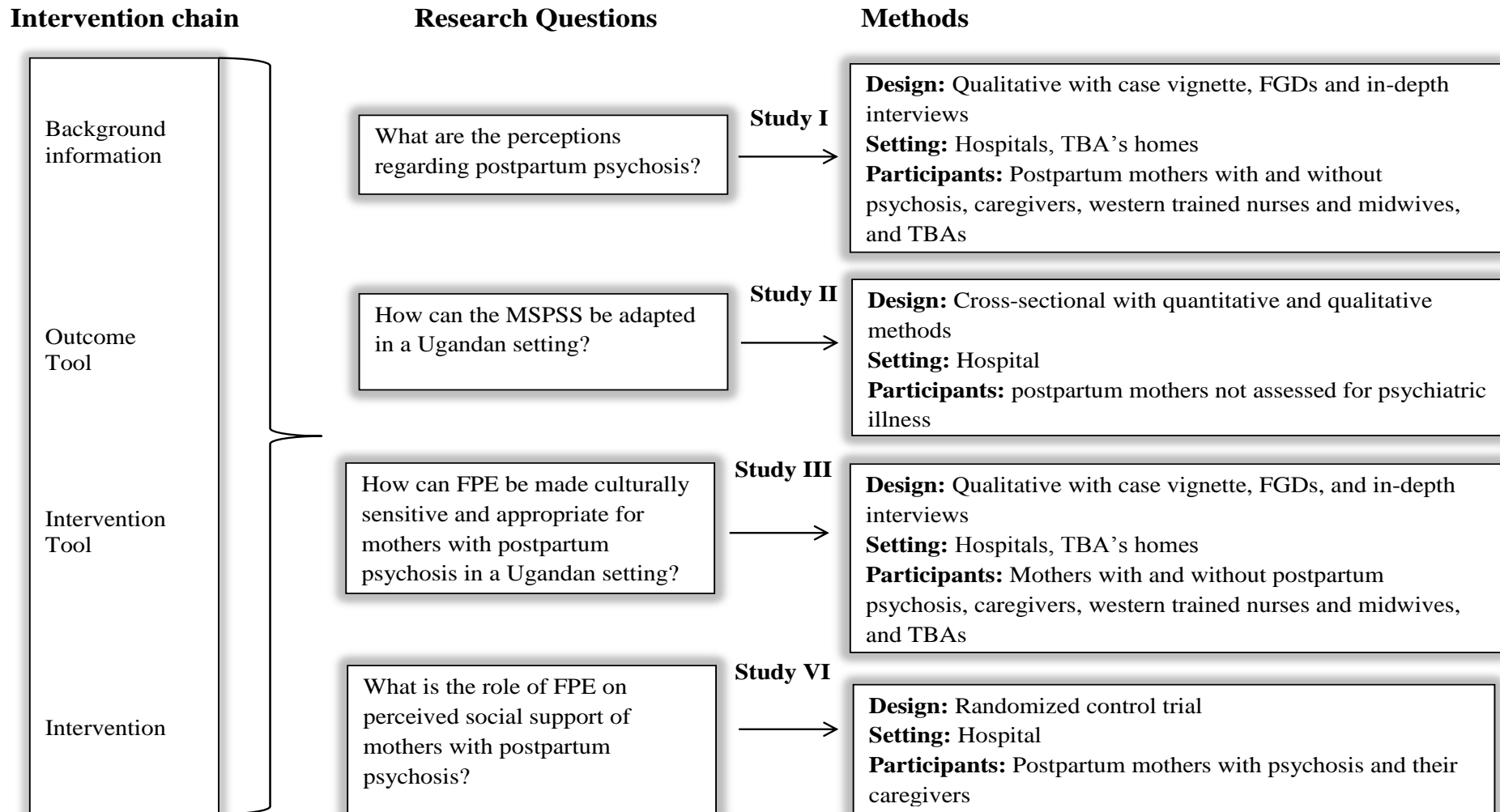


Figure 2. An overview of the research framework

A background to health service provision in Uganda

The health care system in Uganda is composed of the public and the private sectors. At the public sector level, there are two national referral hospitals namely Mulago targeting a population of 2,000,000 and Butabika with an inpatient bed capacity of 500. In addition to health provision, these two referral centers train healthcare providers. Below the national referral hospitals are 11 regional hospitals. These are mini hospitals at the health center IV level.

Below these is the Health Center III which receives referrals from Health Center II and makes referrals to Health Center IV. Health Center IV facility is at the county level and has a target population of 100,000. It has maternity inpatient services. Health Center III is at the sub-county level targeting a population of 20,000. Health center II is the nearest health facility to the community. Health center I caters basically for the community outreach activities like health education, promotion etc. (Health System Profile for Uganda, 2005; Human Resources for Health Country Profile, 2009).

There are a number of categories in the private healthcare provision sector of Uganda. High on the list of the private sector are the facility-based private and not for profit (PNFP) health service providers. These are essentially religious based and they are the Uganda Protestant Medical Bureau with hospitals such as Mengo; Uganda Catholic Medical Bureau with hospitals such as Rubaga; and the Uganda Muslim Medical Bureau with hospitals such as Kibuli. In addition to providing healthcare services, these health facilities are also training healthcare providers.

A second category of private health providers in Uganda are those that are not facility based. They are private but not for profit. Examples of such organizations are the Uganda Red Cross, Save the Children Fund etc. The third category of health care provision which is private but for profit is from the Private Health Practitioners. They are licensed practitioners and mainly provide primary health care services although a few provide specialist care.

A fourth category is the traditional and complementary medicine practitioners who are consulted and used by 60-80% of Ugandans (WHO, 2002). Among these are the Traditional Healers, Bone setters, Traditional Birth Attendants (TBAs) etc. (Human Resources for Health Country Profile, 2009). They commonly are registered in their specific associations at the sub-county and the district levels. These practitioners commonly receive apprenticeship in order to practice and the majority of these do not have formal education. In Uganda, close to 59% of births are attended to by TBAs (UBOS, 2006).

Reports from the Uganda Bureau of Statistics show that from qualitative module findings, an estimated 58% of households in Uganda have a member with a mental disorder. Mental disorders in the general population were rated as follows; posttraumatic stress disorder (9%), depression (20%), manic depression (3%), anxiety (4%) schizophrenia (1%) and individuals with mental disorders having suicidal

tendencies (23%) (Uganda Bureau of Statistics, 2006). Apart from one study in a peri-urban setting that documents the prevalence of postpartum depression at 6.1%, (Nakku et al, 2006), there is currently almost no documented research on prevalence or incidences of maternal mental health problems in Uganda.

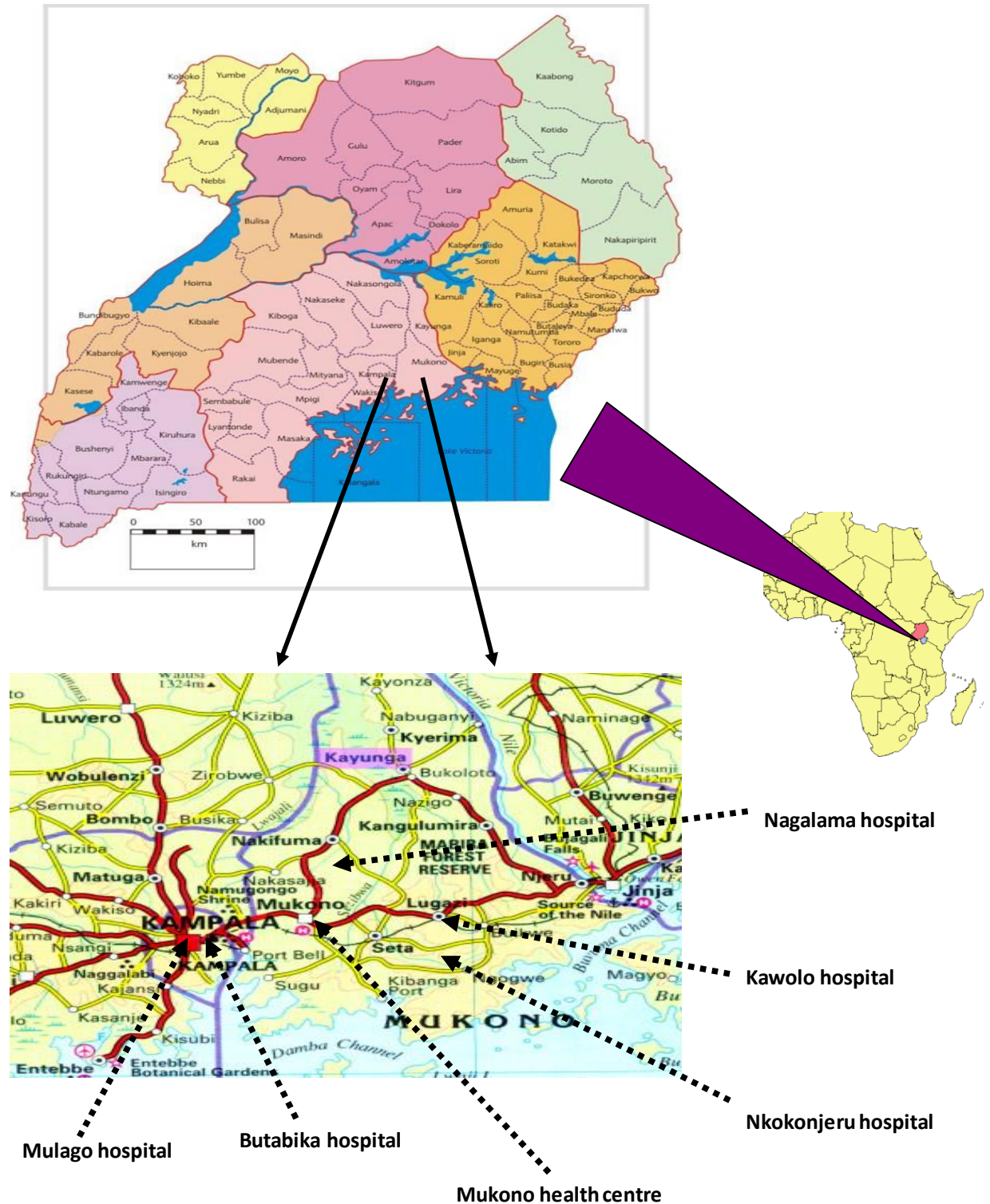


Figure 3. Map of Uganda showing study sites.

Uganda is ranked as one of those countries with a very high birth rate and naturally this high birth rate exposes Ugandan women and their neonates to high risks of death as a result of pregnant complications. The lifetime risk of a Ugandan woman dying due to maternal causes is 1 in every 12. It has been estimated that for every Ugandan woman who dies as a result of a pregnancy related cause, twenty to thirty women will become affected by short term or long term disabilities due to pregnancy or birth complications (USAID Maternal and Neonatal Program, 2010). Perinatal and maternal conditions were ranked highest at 20% among the major causes of mortality and morbidity in Uganda (USAID Maternal and Neonatal Program, 2010).

Box 3. Facts on maternal health in Uganda.

4.2 STUDY POPULATIONS

4.2.1 Study I

The study population consisted of postpartum mothers, their caregivers and healthcare providers who were taking care of the new mothers' maternal health needs. Among the postpartum mothers, we purposively selected who were not known to have mental illness and mothers who were diagnosed with postpartum psychosis based on criteria established in the fourth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV; American Psychiatric Association, 2000). Further, the study population included caregivers for the mothers. The group of healthcare providers was composed of the western trained healthcare providers such as midwives and nurses and the TBAs.

4.2.2 Study II

The study population in the MSPSS adaptation study consisted of healthy mothers who were reporting back to hospital for review at 6 weeks in their postpartum period.

4.2.3 Study III

In culturally making FPE sensitive and appropriate, we recruited psychiatric nurses and psychologists with a special interest in maternal mental health. In addition, mothers diagnosed with postpartum psychosis by using DSM-IV criteria and their caregivers were included into the study population.

4.2.4 Study IV

Study population in Study IV consisted of mothers diagnosed for postpartum psychosis according to the DSM-IV criteria as well as their caregivers.

4.3 INSTRUMENTS AND MEASUREMENTS

4.3.1 Focus group guide with case vignette (Study I)

The case vignette formed the basis of the questions that were asked in the Focus group guide. It was developed by a psychologist and a psychiatrist based on the criteria for psychosis as is stated in the DSM-IV (American Psychiatric Association, 2000). The case vignette illustrated psychosis in the postpartum period. The focus group guide was first written in English, and then was translated back and forth to ensure that the conceptual equivalence of the English and Luganda languages was not lost.

4.3.2 In-depth Interview Guides (Study I)

There were two kinds of in-depth interview guides; one was developed for the women who had been diagnosed with a current psychotic illness in the postpartum period and another one was developed for their caregivers. These in-depth interview guides were unstructured and their aim was to elicit the postpartum mothers' and caregivers' experiences about postpartum psychosis, symptoms, their assumed causes, and the possible treatments.

4.3.3 M.I.N.I. (Studies I, III and IV)

The MINI International Neuropsychiatric Interview (MINI) schedule is a structured diagnostic tool used in the diagnosis of axis I psychiatric disorders (Sheehan & Lecrubier, 1998). It takes about 15 to 20 minutes to administer. This was used to confirm that the postpartum women who were recruited in the study had suffered from a psychiatric diagnosis of psychosis.

4.3.4 MSPSS (Studies II & IV)

The MSPSS is a short self-report questionnaire that was developed in the USA (Zimet, 1988). It has been widely used to assess perceived social support in various populations (Zimet et al, 1990; Eker & Arkar, 1995; Stanely et al 1998; Edwards, 2004). The total scale has 12 items that lie on a Likert scale. Of the 12 items, 4 items are about family social support, 4 items are about social support from friends and the last 4 items ask about social support from a significant other. A high total score is evidence of high levels of perceived social support. The lowest score that a participant could obtain on the MSPSS is 12 and the highest is 60. (See Appendix)

4.3.5 FPE workbook (Study III)

The FPE Implementation Resource Toolkit for the implementation of the evidence-based practices project in The USA (McFarlane & Dixon, 2003) was used in the training of psychologists and psychiatric nurses in the adaptation of the FPE program. The workbook was designed to illustrate all that one needs to effectively carry out FPE for specific disorders. It gives an introduction, an overview of the process, content and duration of FPE. It also elaborately gives a description of the various stages of FPE by describing each phase of the process and giving examples. The adapted version was one for affective disorders because research shows that most postpartum mothers with

psychosis have a psychiatric history of bipolar disorder (Brockington, 1981). The FPE workbook describes how one can go about to ensure fidelity of the process by giving a checklist of the areas that need to be monitored and evaluated. Fidelity refers to the degree or extent to which an evidence-based practice is effectively implemented (Bond et al, 2000).

4.4 DATA COLLECTION PROCEDURES

4.4.1 Study I

To explore perceptions regarding postpartum psychosis, the principal investigator (PI) with one research assistant were trained in qualitative data collection methods. After obtaining relevant ethical permission, the study was introduced to the participants. The PI was the moderator in the focus group discussions and in-depth interviews. The research assistant was the note taker. All interviews were tape recorded with permission from the participants and then transcribed. One participant from each individual focus group was selected to listen to the transcripts from that particular group to ensure that the transcription was a true reflection of what had been discussed in the group (Carr & Kemmis, 1986). When no new information was forthcoming from the focus group discussions and the in-depth interviews, the interviewing was ended.

4.4.2 Study II

Study II entailed the translation of the MSPSS and testing its psychometric properties on postpartum women. The MSPSS was translated into Luganda using standard translation procedures (Herdman et al, 1998). In the forward translation a Luganda translator familiar with English and the terminology used in the MSPSS translated the scale into Luganda. Emphasis was put on conceptual equivalences and we avoided technical terms that were difficult to understand by Luganda speakers in everyday life. An expert bilingual panel for the translated version was convened. This panel identified and resolved contentious expressions and concepts in the forward translation. The Luganda translated version was then translated back into English by another translator with no prior knowledge of the MSPSS.

We then pre-tested the new Luganda version on 20 women Luganda speakers. These participants completed the questionnaire and through cognitive interviewing, they gave explanations of why they had responded the way they did. We also asked them what they thought the items were asking for and then asked them to paraphrase items that they perceived not to be clear. After the translation had been achieved, we developed visual illustrations of the MSPSS Likert scale. We hand drew pictures of a woman with different emotional expressions. This was perfected using computer imaging with help from the medical illustrations department. We made sure that the different pictures of the woman corresponded to the different Likert scale points of 1- strongly disagree to 5-strongly agree by enlisting the help of psychiatrists in the department who were asked to rate the pictures in relation to the Likert points.

Finally, we trained 2 psychiatric nurses and 2 psychology students in administering the MSPSS and after obtaining voluntary informed consent from the postpartum women, the questionnaire was read to the postpartum mothers who would then respond to the questionnaire items.

4.4.3 Study III

An in-depth interview guide was formulated for the psychiatric nurses and the psychologists who were involved in the FPE adaptation process. Prior to the interview, the PI gave an overview of FPE to the psychiatric nurses and the psychologists after which they were provided with a FPE workbook. They read it and gained an understanding of how FPE is carried out elsewhere. Following this the PI gave an overview of FPE to the nurses and psychologists after which an in-depth interview was contacted with each of the nurses and the psychologists on what they thought could be maintained or needed to be changed or to be incorporated in the FPE. They were reminded to keep in mind that the FPE was being modified to cater for the needs of postpartum women with a psychiatric illness in the specific Ugandan setting. Their suggestions were incorporated in a new revised version of FPE. Figure 4 shows the process of making the FPE culturally sensitive and appropriate for mothers with postpartum psychosis in Uganda.

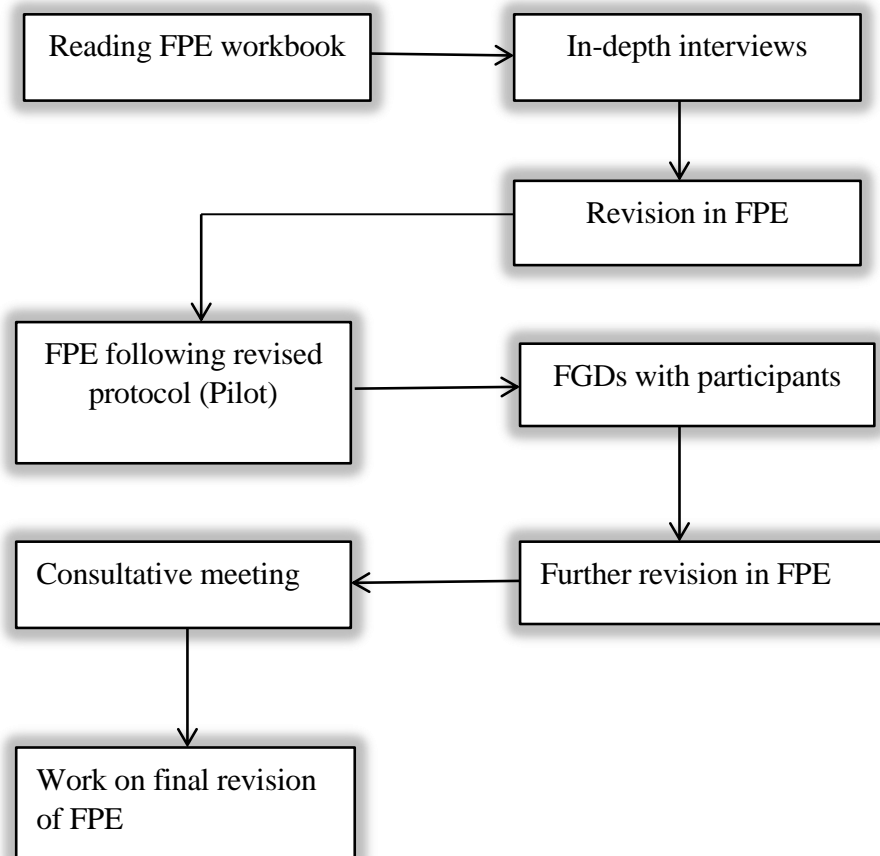


Figure 4. Sequential steps in making FPE culturally sensitive and appropriate

Next, the revised FPE was piloted on 6 pairs of mothers and their caregivers in weekly sessions for 12 weeks. This was followed by focus group discussion with the mothers and the caregivers on their views of the new version of the FPE. They were asked to suggest changes to improve the quality of the FPE. Further changes were incorporated through a consultative meeting with the rest of the stakeholders resulting into a culturally sensitive and appropriate version of FPE for postpartum women with psychosis.

4.4.4 Study IV

This was a randomized controlled trial study. Postpartum women admitted in a psychiatric facility, were assessed for their eligibility into the study. At the time of discharge, the study was described to them. Voluntary informed consent was obtained and baseline data on perceived social support was collected. Following this mothers were randomized into two groups. The intervention group was subjected to 2 hour weekly sessions of FPE with their respective caregivers. The control group was followed every time they came back to hospital for reviews. At the end of 3 months, the mothers' perceived social support was assessed again. Collected data was checked for completion at the end of each day that data was collected.

A randomized profile for recruitment of participants into Study IV is shown in Figure 5. Out of the 139 eligible participants 35 of were excluded. Ten of the mothers dropped out for unknown reasons, 6 relapsed during the study period. We were unable to make contact with 6 mothers and one died. Other reasons for loss to follow up were getting into a new relationship, loss of interest in the study and HIV complications. In total, 104 mothers were randomized into the intervention group (n = 53) and controls (n = 51).

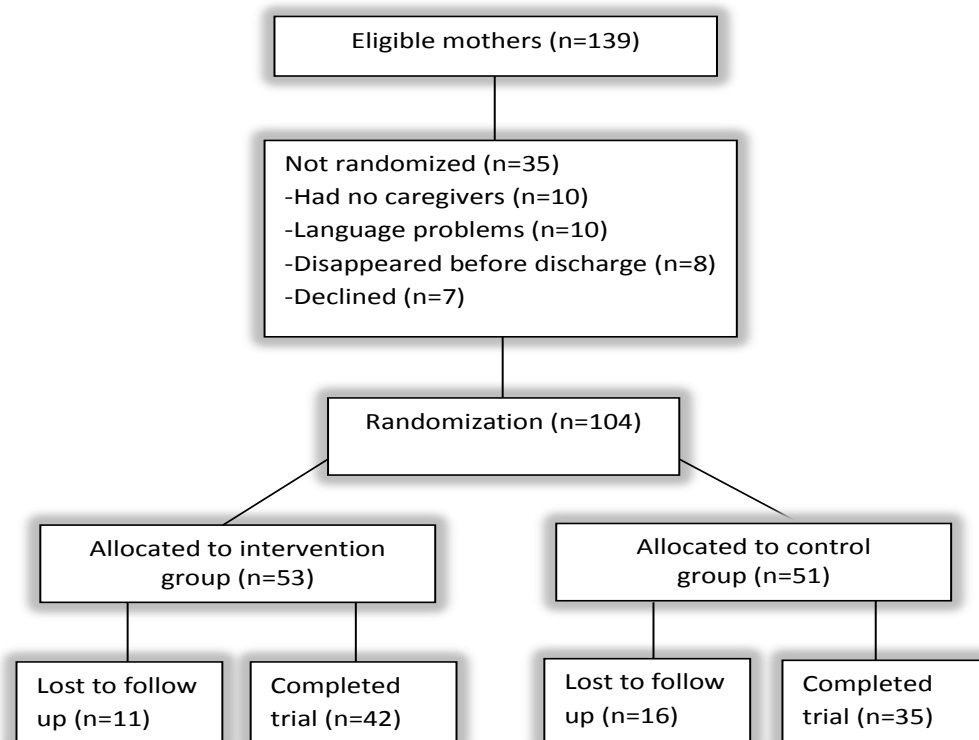


Figure 5. Diagram showing the randomization profile for Study IV

4.5 DATA ANALYSIS

Table 1 gives a summary of the analysis methods used in the studies. Study I employed qualitative thematic analysis. Qualitative analysis was manually performed using guidelines (Basit, 2003) and using thematic analysis (Attride-Stirling, 2001; Braun & Clarke, 2006). The data was transcribed, manually coded then categorized into already preset categories. The coded data was read multiple times by the authors to derive thematic networks and finally global themes and interpretation.

In Study II, both qualitative and quantitative methods in order to adapt the MSPSS questionnaire were used. Reliability coefficients were obtained using cronbach alpha and validity was achieved using exploratory and confirmatory factor analysis.

In Study III, we used an emerging tool of qualitative research which was discussion and consensus. Study III employed tallying and discussions to reach a consensus on what participants thought would work best considering that we did not have a gold standard for analysis of such data.

In Study IV, analysis of covariance and moderation analysis were used in order to determine the effect of FPE on perceived social support of mothers with postpartum psychosis. This was after ensuring homogeneity and adjusting for the baseline perceived social support.

Table 1. An overview of the analysis methods

Analysis	Study I	Study II	Study III	Study IV
χ^2				X
t-test				X
Reliability coefficients		X		
Factor analysis		X		
ANCOVA				X
Moderation analysis				X
Qualitative thematic analysis	X			
Discussion and consensus			X	

4.6 ETHICAL CONSIDERATIONS

The study protocol was presented to the Faculty of Medicine Higher Degree Research Committee for approval. Suggested revisions were made in the study protocol and finally after approval from the Faculty's IRB, permission to carry out the study in the two districts was sought from the Uganda National Council of Science and Technology. The district health officials of Mukono and Kampala districts approved the study. The clinical directors of Mulago and Butabika hospitals where some participants were drawn from also approved the study. The district health officials liaised with the Traditional Birth Attendants Association in Mukono district to enable us to make contact with and interview the TBAs.

We ensured that our participants gave voluntary informed consent. We made sure that participants in the study with mental health problems were not recruited into the study, until they were well enough to give voluntary informed consent. Consent was also obtained from the postpartum mothers to have their caregivers recruited into the FPE intervention. This was done because having the caregivers in the intervention would provide information to the caregivers which information may have been private and confidential. Voluntary informed consent of the participants was given both verbally and in writing. When a participant did not know how to write, we obtained his or her thumb print on the space where he or she would have signed to show that the participant willingly participated in the study.

5 RESULTS

5.1 STUDY I

The responses to perceptions regarding postpartum psychosis were grouped into 5 categories as is seen in Table 2. From the case vignette and the focus group questions, participants recognized the case vignette as one for a woman with postpartum psychosis or the commonly used lay term of *amakiro*. They expounded on the symptoms found in the case vignette. Participants further went ahead and described other symptoms that were not in the case vignette but symptoms that they knew were synonymous to postpartum psychosis or *amakiro*.

Safety of the infant in the event that the mother developed this illness was emphasized. Participants pointed out that if a mother's condition was severe according to them, then the mother had to be promptly referred.

Further perceptions that related to the presumed cause of the condition were discussed by the participants. High on this list was the perception that if a pregnant woman was adulterous during the time she was pregnant, then she would develop postpartum psychosis in the postpartum period. If the spouse of the pregnant woman was promiscuous when the woman was pregnant, then the woman in her postpartum period would develop psychosis or *amakiro*.

The cause of adultery was further elaborated to even include others in the community. It was believed that if a pregnant woman was careless enough as to sit in a place where someone who had just had an adulterous encounter had just sat, then the woman could develop postpartum psychosis. Supernatural causes such as witchcraft or *lubaale* which is a clan illness were also mentioned.

Another set of presumed causes included physical causes such as infections, working too hard, a history of mental illness, changing sexual partners, first time motherhood and alcohol withdrawal after birth.

The category regarding perceptions treatment options had themes of traditional, western and faith based modes of treatment. Traditional modes of treatment to cleanse the postpartum woman were used. These were the use of herbs, and the personal effects of the spouse. The same kind of treatment would be administered if the woman developed the condition but also when the woman had to use preventive measures to inoculate herself against developing the condition in the postpartum period. Along with other treatments was faith healing. This was commonest in those who believed in the power of prayer. Biomedical treatment was another option.

Table 2. A summary of the categories and themes of perceptions on postpartum psychosis.

Category	Theme
Recognition	<ul style="list-style-type: none"> • Lay concept- <i>Amakiro</i> • Physical symptoms • Psychological symptoms with hallucinations • Psychological symptoms of affect such as anger, or thinking too much • Psychological symptoms of a behavioural nature such as poor sleep, disturbed appetite, urges to do harm to the baby
Safety for the infant and referral	<ul style="list-style-type: none"> • Postpartum mother being a danger to the infant • Prompt referral on failure to improve with traditional remedies and depending on severity
Presumed causes	<ul style="list-style-type: none"> • Adultery of postpartum mother during pregnancy • Promiscuity of postpartum woman's spouse during pregnancy • Adultery by proxy and carelessly sitting in an unclean places • Supernatural causes including ancestral spirits and witch craft • Physical cause related to infection • Working too hard • History of mental illness • Change of sexual partners • First-time motherhood • Alcohol withdrawal after birth
Treatment options	<ul style="list-style-type: none"> • Traditional treatments included the use of herbal baths and bathing using the personal effects of the spouse during pregnancy • Biomedical treatment was used concurrently with other modes of treatment • Faith healing
Preventive options	<ul style="list-style-type: none"> • Traditional options same as for treatment but the man also has a responsibility of bathing using herbs when he knows that he has been sleeping around during the time when the woman is pregnant

5.2 STUDY II

The MSPSS was translated back and forth and picture illustrations were incorporated. To determine the internal reliability of the MSPSS, the cronbach alpha was estimated for the three sub-scales (i.e., Family, Friends, and Significant Other) as well as for the entire scale. The mean and the cronbach alpha of the MSPSS for the Family subscale

was 3.60 (SD= .085) and .82, respectively. Corresponding figures for the Friends subscale were 2.92 (SD= .203) and .80, for the Significant Other subscale 4.00 (SD= .060) and .79. Finally, the full scale of the MSPSS had a mean of 3.51 and the cronbach alpha of .83.

Validity of the scale was determined by performing factor analysis which identified 3 factors and these were Family, Friends, and Significant Others. A dendrogram showed that items in these 3 subscales were closely linked. (see Figure 6).

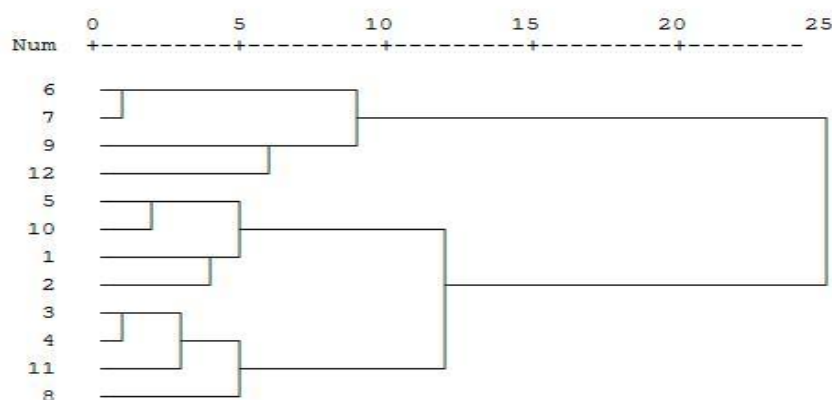


Figure 6. Correlation analysis depicting a strong relation between subscale items of the MSPSS.

Sub-scale items 6, 7, 9 and 12 were closer together and they all measured the Friends subscale. Items 5, 10, 1, and 2 were close together in the dendrogram and these measured the Significant Other subscale. Items 3, 4, 11 and 8 were close together in the dendrogram. These measured the Family subscale and the dendrogram clearly showed that all subscale items were linked and that they ultimately measured the same construct of social support.

5.3 STUDY III

Issues raised in the process of FPE were in the process and the content. Emphasis was put on effective communication, having FPE moderators who had a similar cultural background with the participants because with this participants would be understood in their own context. Appropriate dress by the moderators, and involving only one family member were pointed out. Time keeping issues and the fact that the population has a low literacy rate were also considered. In the theme of content, lay perceptions regarding psychiatric illness causation, and treatment were incorporated. Family planning education was considered because postpartum women with psychosis needed to make informed decisions about their sexuality and conception. Breastfeeding issues to demystify cultural perceptions were also incorporated. Income generating activities, the premorbid and morbid personalities of the patients were emphasized.

5.4 STUDY IV

One hundred and four mothers were randomized into the intervention group ($n = 53$) and the control group ($n = 51$). There were no significant differences between the intervention and control groups on dropout rate ($X^2 = .107$, $p = .744$).

ANCOVA analysis with intent to treat was performed. After adjusting for baseline perceived social support, postpartum mothers in the intervention group had higher levels of perceived social support than the control group ($F = 6.31$, $p = .01$). The effect size was moderate at .35. The moderation of marital status was not statistically significant but there was a big effect size for mothers who were married at .57 compared to those who were not married at .09 (see Figure 7). Mothers in the intervention group who were married tended to have higher perceived levels of social support than those who were not married.

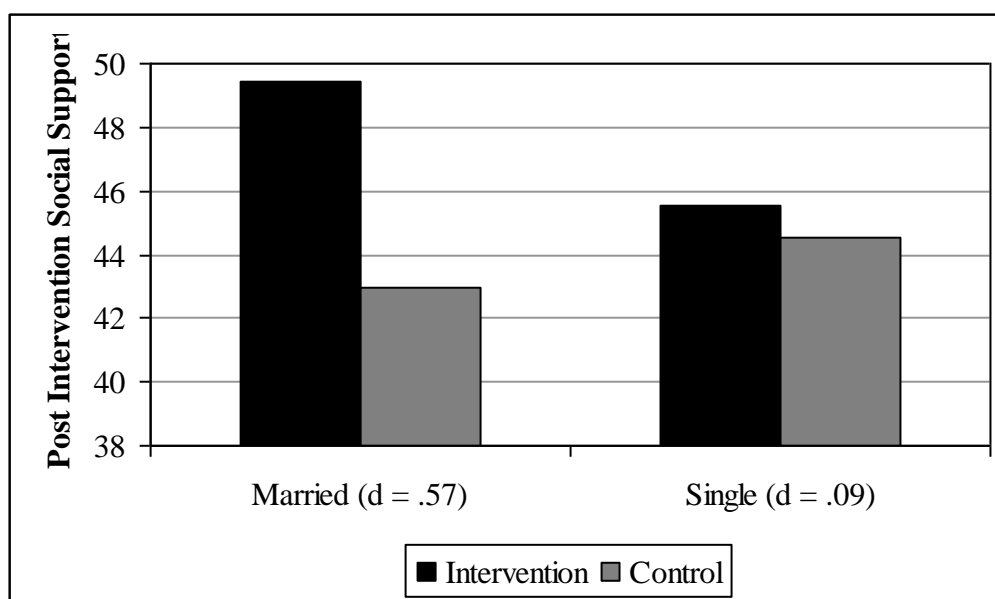


Figure 7. Intervention effect by marital status.

6 DISCUSSION

We investigated the impact that FPE would have on the perceived social support of postpartum mothers with psychosis in Uganda. To appropriately achieve our aim, we ensured that we obtained background information on perceptions regarding postpartum psychosis in the setting. Secondly, we wanted to have an outcome measurement by which we would reliably determine whether our FPE intervention was effective. To this effect, we adapted the scale that measures perceived social support in the setting for our outcome measure. Thirdly we carried out a sensitivity and appropriateness study of FPE that specifically targets postpartum mothers in this setting and this was the intervention by which we aimed to achieve our main objective. The different study results are discussed in the order that they were carried out to finally lead us to the discussion about investigating the role of FPE on perceived social support of postpartum mothers with psychosis in a Ugandan setting.

6.1 PERCEPTIONS REGARDING POSTPARTUM PSYCHOSIS

One of the significant findings on perceptions was that postpartum psychosis was well recognized by participants and it was locally referred to as *amakiro* (Cox, 1979; Neema, 1994). This local term according to the participants, depicted all illnesses in the postpartum period ranging from physical to mental health problems. Another significant finding was that participants recognized the severity of the condition and prompt referral to a health facility by the western trained healthcare providers, the TBAs and the lay people was mentioned. The condition was appropriately taken to be an emergency as is the case elsewhere (Spinelli, 2009).

A number of presumed causes were elicited from the participants. High on the list was the belief that if a pregnant woman slept with anybody else other than the spouse, then she would develop psychosis in the postpartum period. This lay perception was documented early in the 1970s and 1990s and it still holds up to this time (Cox, 1979; Cox, 1999; Neema, 1994). This fact points to how enduring perceptions can be. This lay perception of adultery was however dependent on whom you asked. If a respondent was directly affected by the condition, then causation of postpartum psychosis by adultery was not considered a possible cause. It was easier for participants not directly affected by the condition, to attribute the cause of postpartum psychosis to the immoral behavior of the postpartum mother during her pregnancy than those who were affected by the condition. Postpartum mothers with psychosis pointed out that the condition could be a result of infection of the mother. Postpartum psychosis with an organic origin has been mentioned in literature (Brockington, 2006).

Although adultery of the woman was the main lay explanation for causation of psychosis in the postpartum period, other perceived causes were pointed out. If the postpartum mother had not been promiscuous during the pregnancy, then it was possible that her partner had been promiscuous. So either way the postpartum mother was disadvantaged and subjected to distress either because others perceived her to be the cause of her condition or that her partner was promiscuous. This belief was strongly

held even by the TBAs who assist about more than half of all pregnant women (Uganda demographic and healthy survey, 2000-2001) during the delivery of their infants. In addition if the woman did not use preventive measures while pregnant then there was a possibility that she could develop postpartum psychosis.

Unique as it is because it occurs in the postpartum period, the condition was still perceived to be caused by supernatural forces of witchcraft and *lubaale*. Postpartum psychosis is a mental illness like other mental illnesses in this setting and the explanations that pertain to causes of other mental illnesses in this setting were still mentioned for this condition (Orley, 1970; Okello & Musisi, 2006; Abbo et al, 2008).

Traditional methods of treatments were recommended however depending on the severity of the condition, western treatment could be sought. There was a relationship between the assumed cause and the mode of treatment. It was not possible to know when supernatural forces would strike and cause mental illness. Therefore before the woman developed the condition, it was important to protect herself by using preventive measures of herbal treatments. Since it was difficult to know if the woman or the partner were promiscuous, it was important that she uses preventive measures during pregnancy. By using the herbal remedies she would prevent psychosis that could be caused by her own promiscuity, that of her spouse, and she would also be able to keep the witchcraft and *lubaale* at bay. A limitation to this study is that it was a qualitative study and therefore our study findings are not generalizable to the rest of the country.

6.2 ADAPTATION OF THE MSPSS

A significant finding was the effective back and forth translation of the MSPSS. By using Herdman's standard model of translating questionnaires (Herdman et al, 1998), we were able to effectively translate the MSPSS. The proof of this is in the reliability and validity work we carried out on the MSPSS. We were able to obtain high reliability coefficients for the translated Full scale version and our findings were similar to previous reliability findings on the MSPSS (Zimet et al 1988; Zimet et al, 1990). When we assessed the reliability of the MSPSS in study IV in the baseline and posttest data collection, it was high and results were consistent with those in the adaptation study.

The original MSPSS by Zimet consists of three subscales namely the Family, Friends, and the Significant Other subscales. Their reliability in this study was ascertained by use of cronbach alpha and all the subscales demonstrated good reliability coefficients at Family = .82, Friends = .80 and Significant Other = .79. This finding was similar to other studies (Eker, & Arkar, 1995). Factor loadings on the three different scales were high. These indicated that the participants in the adaptation study were able to differentiate between the three different sources of social support (Zimet et al, 1988).

6.3 SENSITIVITY AND APPROPRIATENESS OF THE FPE

We explored issues that would make FPE culturally sensitive in a Ugandan setting. Results from this study indicated that the basic principles underlying the formulation of FPE cannot be underestimated. The basic therapeutic elements that are necessary to work effectively in a cross-cultural setting arose in this study. This shows that when adapting psychological interventions, there are universally accepted principles that have to be adhered to so that psychological programs do not lose their fidelity (Singer, 2003).

In order to make FPE culturally sensitive, our study came up with issues that reflected the social-cultural and economic realities of the population. Uganda's literacy rates have been low although they are now being enhanced by universal primary education (UNDP Millenium Goals Report, 2008). In accordance with this fact, the participants opted for a type of FPE that would cater for the low literacy levels of postpartum mothers. Literature indicates that majority of women with postpartum psychosis many times have a psychiatric history of bipolar disorder (Brockington, 1981).

We incorporated the cultural lay perceptions regarding postpartum psychosis. Explanatory models of illness causation may determine whether an individual will comply with treatment or not (McCabe & Priebe, 2004). Hence the incorporation of the Ganda perceptions on postpartum psychosis in order to formulate a program that would demystify the idea that postpartum psychosis was brought on by adultery of the woman or the man.

Breastfeeding issues were incorporated since they were raised by the participants. Unknown to some of us in the adaptation of FPE was the fact that there were cultural issues that had not been tackled and these were perceptions relating to breastfeeding when a woman develops postpartum psychosis. In one of the discussions the cultural perception that if a woman breastfeeds while with psychosis, then the child later on grows and develops a similar mental illness. We therefore incorporated breastfeeding in order to demystify this perception. Postpartum mothers and their caregivers understandably wanted family planning to be incorporated in the FPE so that the women would be able to make informed decisions about their conception.

Participants were preoccupied with the idea that they should obtain skills that would allow them to live an independent life and since obtaining employment was difficult, we opted to come up with income generating activities that the women would initiate without being employed by others. This made sense because Uganda's unemployment is about 3.5% and its underemployment is about 17% which is high (CIA World Fact book, 2010).

6.4 THE ROLE OF FPE ON PERCEIVED SOCIAL SUPPORT

We hypothesized that the FPE intervention would produce a positive effect on social support of postpartum mothers with psychosis. Our results showed that FPE given at weekly sessions to postpartum mothers and their caregivers for 12 weeks improved

perceived social support of the postpartum mothers. FPE has been documented to produce positive effects in domains other than perceived social support (Miklowitz, 2003). We obtained significant statistical results regarding the role of FPE on perceived social support; however the effect of the intervention was rated moderate. There are several possibilities of why the effect was moderate. One is that most FPE programs have a minimum duration of 6 months (McFarlane, 2003). Ours took three months. Secondly perceived social support does not necessarily yield results that are comparable to other domains like fewer relapses or higher survival intervals that have been evidenced in other studies (Miklowitz, 2003) because they are different constructs. Our study showed that married postpartum mothers benefitted more from FPE than postpartum mothers who were not married. This is probably due to the fact that marriage is a proxy of social support (Hewitt et al, 2010). Finally we lacked previous studies to directly compare our results. A limitation to our study was that previous findings on the efficacy of FPE were done in other outcome domains other than perceived social support.

6.5 METHODOLOGICAL CONSIDERATIONS

6.5.1 Strengths

A major strength of the methodology used in the thesis is that we adapted our measurement of outcome and also endeavored to make our intervention measurement culturally sensitive and appropriate for the population and then finally pilot tested the methodology before carrying out the randomized control trial in Study IV. The PI was directly involved in the qualitative data collection of Studies I and III. This was because the investigator is assumed to be a research tool in qualitative research and therefore cannot disentangle him or herself from the data collection (Patton, 1990). Contrarily in order to avoid investigator bias, the PI was not directly involved in the data collection of Studies II and IV which were quantitative in nature.

Credibility and dependability of qualitative research in Studies I and III

To ensure that the data collected would be trustworthy, the moderator and the note-taker were trained in qualitative data collection and analysis methods. There was also constant consulting with the qualitative research expert. During the process of seeking voluntary informed consent, informants were provided with the option of not participating in the study. We pointed out that their participation was voluntary and they could withdraw from the study at any time. This helped us in ensuring that informants that we had in our study were genuinely interested and would hopefully give honest responses. We emphasized from the onset of the discussions that informants should be truthful in their responses. There was probing during the interviewing and by this we were able to validate participants' responses. Probing has been documented as one of the ways by which one can ensure that participants' responses are truthful because it removes incongruences (Shenton, 2004).

Debriefing at the end of each focus group discussion enabled us to further understand and validate participants' responses. It also helped us to modify our pre-existing

perceptions about the topic of *amakiro*. In addition to debriefing we used peer scrutiny and with this we were able to refine our methods. For example in exploring perceptions in the beginning we had only explored perceptions of the community namely of postpartum mothers without psychosis, their caregivers, and of those involved in the delivery of infants. Through feedback, we learnt that the study would be more valid if we included mothers with postpartum psychosis since these were the main stakeholders. With this there was further triangulation of data sources and we elicited perceptions that mothers with psychosis have.

To further improve on the credibility and dependability of the data collected in the qualitative Studies I and III, we triangulated various methods of data collection. In Study I, we obtained information from focus groups. This allowed us to obtain spontaneous responses from participants who were also able to build on each other's responses. We were hence able to obtain several perspectives from the topic of postpartum psychosis because we had many informants at the same time. We obtained information which may have been difficult to come by if we had not used focus groups. We were finally able to obtain an insight into the community's shared understanding of postpartum psychosis and these were all advantages of focus groups (Gibbs, 1997). We employed in-depth interviews for Studies I and III and this enabled us to tap into the advantages of using one on one interviewing. First the informants that we had for the in-depth interviews were with rich experiences and therefore they provided information that we could not obtain using focus groups (Boyce & Neale, 2006).

In Study III we first collected data using in-depth interviews. Later on we substantiated this data with a consultative meetings and discussions thereby involving all stakeholders. Then we carried out a FPE program in which observation as a data collection method was done. The advantage of observation is that it allowed us to observe incongruences between what people said and how they behaved and we were able to make a follow up on these incongruences afterwards (Patton, 2002). In the absence of a gold standard of adapting FPE, we employed discussions and these were an added advantage because they were argumentative, and participants were able to give justifications for their views which would not have been possible with other qualitative methods. Discussions enabled the pluralism of views to come out and there was an opportunity for all participants to give reflective comments on the sensitivity and appropriateness of the FPE program.

In Study III efforts were made to adhere to the set norms of standard FPE as much as possible by using a standard fidelity scale for FPE (Bond et al, 2000). Finally as a means of ensuring that the delivered FPE was of high quality, and that moderators were not burnt out during the process of FPE, the moderators had supervision on a weekly basis by a senior psychologist in order to obtain support especially on issues by which they were challenged with while carrying out FPE.

At the time of the study inception, there was hardly any literature that pertained to the use of the MSPSS in an African setting. We adapted the MSPSS questionnaire on a

similar population. We therefore translated the questionnaire back and forth following standard procedures (Herdman et al, 1998). We ensured that the conceptual equivalency of the questionnaire items was maintained. Following this, we tested the reliability and the validity of the translated version of the MSPSS. We again tested the reliability of the MSPSS when we collected data in Study IV.

The original MSPSS was designed to cater for individuals with a minimum third grade level of education (Stanley et al, 1998; Zimet et al, 1988; Zimet et al, 1990). Due to cultural attitudes held strongly against educating the girl child (Womenwatch, 2011), the levels of literacy in the postpartum mothers' population were presumed to be lower than those in the general Ugandan population. Indeed Uganda's literacy level for its female population was 57.7% compared to its male population 76.8% (CIA World Fact Book, 2010). We therefore went ahead to cater for mothers who may never have had a chance to go to school. We did this in mainly three ways. First, with permission from the MSPSS developer, we decreased the number of responses that one could make on any one item of the MSPSS from the original 7 to 5 (strongly disagree, disagree, neutral, agree and strongly agree).

Secondly, we hand drew picture illustrations with matching facial emotional expressions corresponding to the 5 point responses (see Figure 8). We hoped that even when a postpartum mother found difficulties in deciding where she fell along the 5 point continuum, the picture illustrations would aid her in making up her mind. Thirdly, the questionnaire was interviewer administered to ensure that all postpartum mothers understood the question items in the same way.

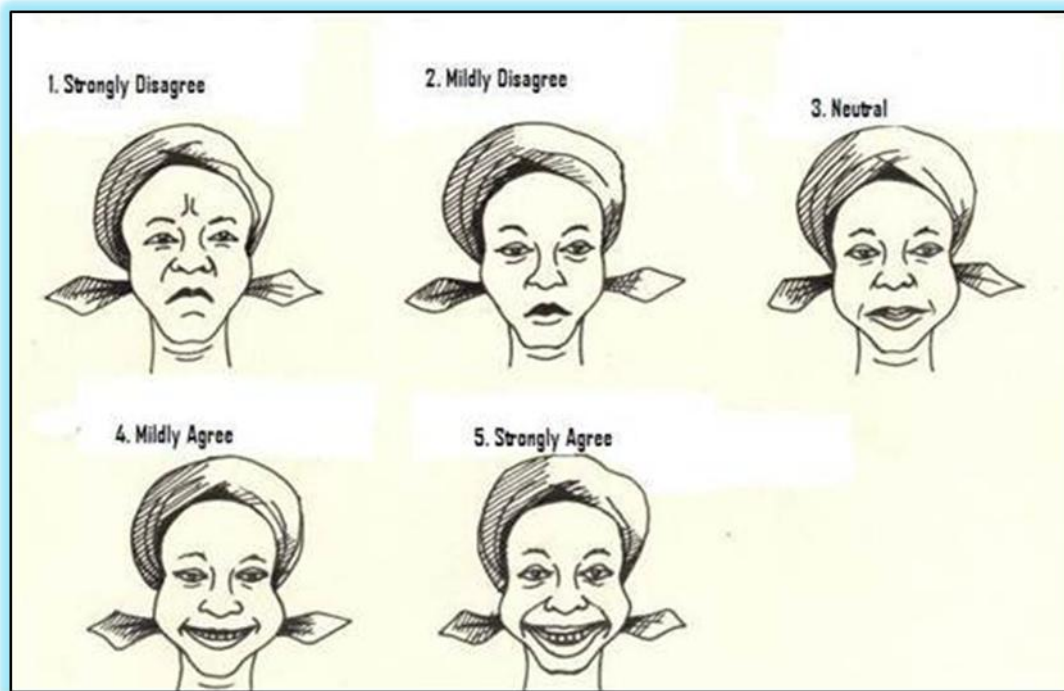


Figure 8. Illustration of the MSPSS facial emotional expressions.

6.5.2 Limitations

First of all, part of the data collection for Study I was carried out in a hospital setting where postpartum mothers with psychosis had been admitted. It is possible that their responses were biased because of the setting. They could have felt that they had an obligation not to mention their lay perceptions regarding postpartum psychosis since they were in a hospital setting. However considering that people with mental illness are highly stigmatized in their communities and that having postpartum psychosis in this setting has negative connotations in the community, we perceived that the most appropriate place to interview the mothers and their caregivers would be in the hospital setting.

Secondly apart from one cultural adaptation study that was done in the USA, literature on the process of adaptation of the FPE program for which we could base our methodology on for Study III was scarce. We therefore had no gold standard for culturally making FPE sensitive and appropriate in this particular setting. However, the fact that we endeavored to bring all stakeholders on board and that we tried to adhere to the FPE fidelity scale checklist, we believe that the adapted version of FPE is appropriate and especially so because it yielded positive results in Study IV.

Study IV being a psychosocial intervention, we were not able to come up with a placebo treatment for the control group. In order to come up with a placebo we would need to have a treatment that appeared to be similar to the intervention but there was none in this cultural setting that we could compare the intervention with since there is scarce literature documenting adaptations of psychosocial treatments in Africa settings.

6.6 CONCLUSIONS

- Lay perceptions regarding postpartum psychosis in central Uganda have not changed in the last 30 years. It is still perceived that if a postpartum woman develops psychosis, then she was adulterous while pregnant or her spouse was adulterous when she was pregnant. It was also reported that postpartum psychosis can be caused by supernatural forces such as witchcraft and *lubaale*. The other perceptions relate to treatment and prevention which are directly related to the cause of the condition. Postpartum mothers and their caregivers who were directly affected by the condition believed that there were other causes of psychosis other than adultery and witchcraft. They mentioned infections, alcohol withdrawal, and working too hard after birth.
- Although traditional remedies are recommended, when the condition is severe then prompt referral to western treatment is the treatment of choice
- Through back and forth translation and by determining reliability and validity of the MSPSS, the instrument was successfully adapted. The MSPSS demonstrated cross-cultural stability of the three subscales and its full scale and hence it can reliably be used in a Ugandan setting.
- All stakeholders namely postpartum mothers with psychosis (patients/consumers) their caregivers (family) and professionals (psychiatric nurses and psychologists) were brought together in order to come up with a FPE

version that would be culturally sensitive and appropriate. Through consultative meetings, and a pilot phase, an adapted version that reflected the social cultural and economic realities of this population was formulated. The basic assumptions underlying all other psychological interventions did apply to this study. However changes were demystifying perceptions of causation of psychosis in the postpartum period, the myths held about breastfeeding while ill, family planning and income generating activities.

- FPE has a positive impact on perceived social support. Postpartum mothers with psychosis improved on their social support when they were involved with their caregivers in a 12 weekly program of FPE. Finally family psychoeducation might be one way by which cultural perceptions regarding postpartum psychosis could be demystified.

6.7 RESEARCH IMPLICATIONS

- There is a need to carry out an effectiveness study and if its outcomes are similarly positive, then the adaptation of FPE for postpartum mothers with severe psychiatric illness should be carried out nationwide.

6.8 TRAINING AND CLINICAL IMPLICATIONS

- The training of healthcare providers in maternal health ought to embrace the cultural contexts within which patients and the community explain causation of illness and treatment. The results from further research on the effectiveness of FPE should direct the training of healthcare providers in FPE and subsequently guide their clinical work.

6.9 POLICY IMPLICATIONS

- After successfully implementing all the above, then FPE should be able incorporated in the care of postpartum mothers in Uganda.

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9 APPENDIX

MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT (ZIMET, DAHLEM, ZIMET & FARLEY, 1998)

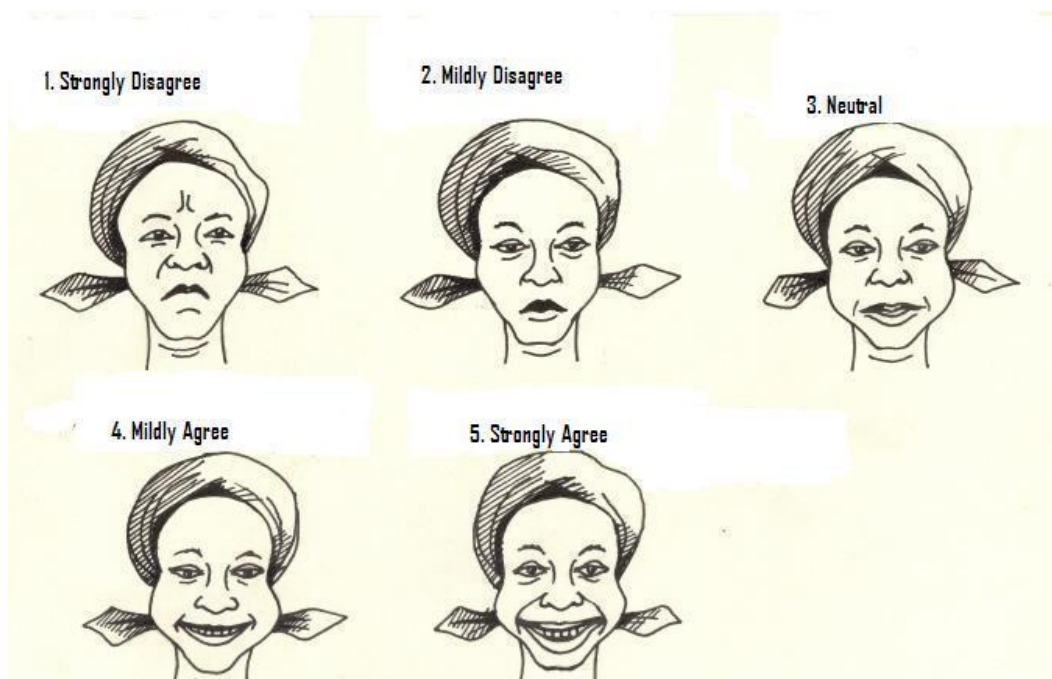
Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Write the number that corresponds of how you feel in the provided space along the statement. For example:

There is a special person who is around when I am in need.

3

The number 3 corresponds to the picture of a woman who feels neutral about her response.



1. There is a special person who is around when I am I need.

☐

2. There is a special person with whom I can share my joys and sorrows.

☐

3. My family really tries to help me.

☐

4. I get the emotional help and support I need from my family.

☐

5. I have a special person who is a real source of comfort to me.

☐

6. My friends really try to help me.

☐

7. I can count on my friends when things go wrong.

☐

8. I can talk about my problems with my family.

☐

9. I have friends with whom I can share my joys and sorrows.

☐

10. There is a special person in my life that cares about my feelings.

☐

11. My family is willing to help me make decisions.

☐

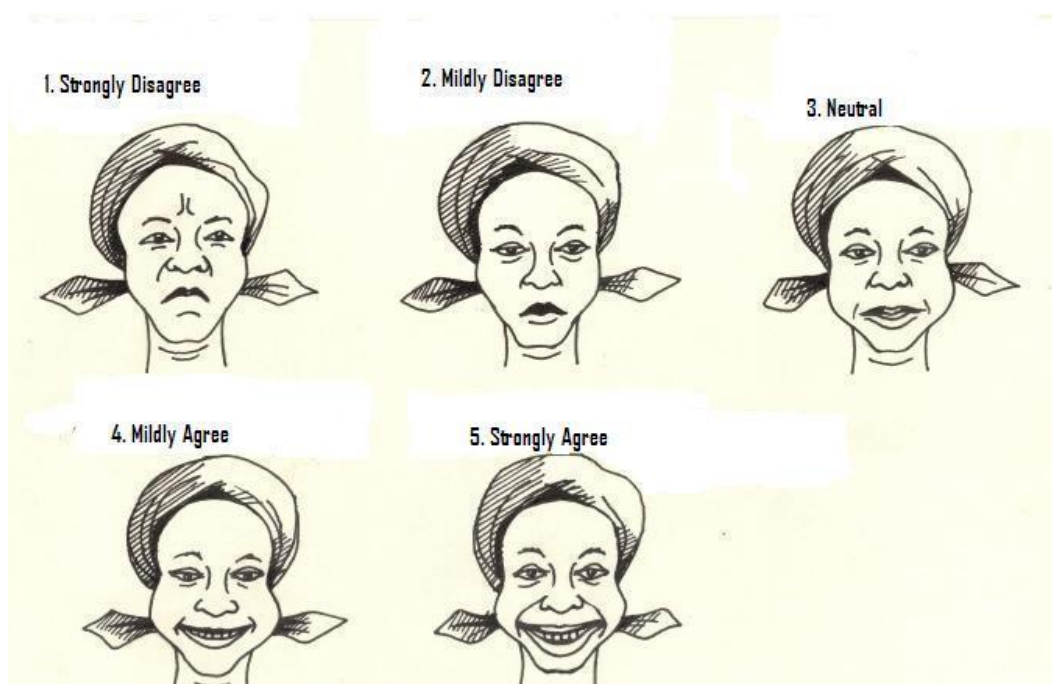
12. I can talk about my problems with my friends.



Engeraageranya y’embudaabudda (MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT) - (ZIMET, DAHLEM, ZIMET & FARLEY, 1998)

Ebyokukola: Twagala okumanya endowooza yo ku biwandiiko bino. Soma bulungi ekiwandiiko ku buli lunyiriri ng’olaga ky’okirowoozaako

Endagiriro



Wandiika ennamba mu ssa (oba akasanduko) akali ku nkomerero ya buli lunyiriri ekkiriziganya n’engeri gyolowoozamu.

Ekyokulabirako:

Waliwo omuntu ow'enjawulo ambudaabuda bwe mba mu bwetaavu.

3

Nnamba 3 ekkiriziganya n'ekifaananyi ky'omukazi addamu nga teyeekubiira.

1. Waliwo omuntu ow'enjawulo ambudaabuda bwe mba nga mu bwetavu

2. Waliwo omuntu ow'enjawulo gwe nsobola okubuulira ku sanyu lyange
n'ennaku yange

3. Ab'oluganda lwange bafuba nnyo okunnyamba.

4. Nfuna abambudaabuda n'obuyambi bwe nneetaaga okuva mu b'oluganda
lwange

5. Nninayo omuntu ow'enjawulo atansuulirira.

6. Mwikwano gyange bafuba nnyo okunnyamba

7. Mwikwano gyange tebansuulirira nga waliwo ekitagenze bulungi.

8. Nsobola okweyabiza ebizibu byange eri ab'oluganda.

9. Nninayo mikwano gyange be mbuulirako ebinsanyusa n'ebinnakuwaza.

10. Waliwo omuntu ow'enjawulo mu bulamu bwange afaayo okumanya embeera gye ndimu.

☐

11. Ab'oluganda lwange beetegefu okunnyamba okusalawo eky'okukola.

☐

12. Nsobola okwogera ku bizibu byange ne mikwano gyange.

☐